"We have a very monolingual mindset": Considerations of language in Culturally and Linguistically Diverse families living with Autism Spectrum Disorder.

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Abstract

Developmental disorders such as Autism Spectrum disorder (ASD) pose challenges for many families. This is especially true for families of culturally and linguistically diverse (CALD) backgrounds who are newly arrived in a country of resettlement. The literature, though limited, suggests that language barriers and cultural differences present significant obstacles in the ASD process. As such, this qualitative study aimed to explore what barriers or facilitators exist for newly arrived CALD families, paying specific attention to language. Semi-structured interviews were conducted with 12 participants, all healthcare service providers with specific experience working with ASD diagnosed clients and their families. All interviews were transcribed, then analysed using thematic analysis. Analysis returned four overarching themes that best explored the aims of this study. Overall, findings suggested that there were significant cultural differences regarding ASD, that language affected every stage of ASD diagnosis and working with CALD children, as did resettlement challenges. Empowerment of families and cultural responsivity of services were cited as important facilitators for best practice. This study hopes to expand research and improve practice so service providers will better accommodate linguistic barriers, and practically acknowledge the cross-cultural disparities of ASD.

DECLARATION:

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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CHAPTER 1

Introduction

1.1 Overview

Developmental disorders such as Autism Spectrum Disorder (ASD) are challenging to identify and diagnose for various reasons, such as variable symptomatology, similarities with other disorders and a strong dependence on caregiver's information. (Huerta, & Lord, 2012). This is more challenging for culturally and linguistically diverse (CALD) families who are newly arrived in a country, as behavioural and linguistic norms differ cross-culturally. This makes recognising contextually relevant atypical behaviours difficult (Norbury & Sparks, 2013; Perepa, 2014; Wilder, Dyches, Obiakor, & Algozzine, 2004). Furthermore, examining language and communication when the child and diagnostician do not speak the same language raises numerous issues (Verdon, Mcleod, & Wong, 2014; Verdon, Mcleod, & Wong, 2015). It is also important to understand how ASD is perceived within CALD communities, including whether it is even recognised as a developmental disorder (Bolton, McDonald, Curtis, Kelly, & Gallagher, 2014; Fox, Aabe, Turner, Redwood, & Rai, 2017; Graham, Minhas, & Paxton, 2016), given that previous research suggests that ASD is not recognised across all cultural contexts (Fox et al, 2017). This study aimed to investigate how ASD is perceived within newly arrived CALD communities in Australia. It also explored potential barriers and/or facilitators to ASD service access for newly arrived CALD communities, with a specific focus on language.

1.2 Definitions and Terminology

1.2.1 Defining Autism Spectrum Disorder

ASD, as defined in the *Diagnostic and Statistical Manual of Mental Disorders (5th Edition) (DSM-5),* is a neurodevelopmental disorder categorised by deficits in areas pertaining to social interaction and communication. These include difficulties in social reciprocity, nonverbal communication behaviours, and developing, maintaining and understanding relationships. These symptoms present alongside the occurrence of restricted, repetitive patterns of behaviour, interests or activities (5th ed.; DSM-5; American Psychiatric Association, 2013). The severity of how these symptoms present vary between individuals. As this thesis has a specific focus on language, it is important to note the presentations of language impairment in ASD. While some individuals show no language impairment, others may be completely non-verbal (no intelligible speech). Language impairment may present through the use of single words only or phrase speech, (spontaneous and meaningful three-word utterances sometimes including a verb) (Klein-Tasman, van der Fluit, & Mervis, 2018). Often, receptive language (ability to understand the information being received – words or sentences, written or verbal) may lag behind expressive language (ability to convert thoughts into grammatically accurate words and sentences) (5th ed.; DSM-5; American Psychiatric Association, 2013).

1.2.2 Defining Culturally and Linguistically Diverse (CALD)

The phrase "culturally and linguistically diverse" (CALD) refers to those individuals whose cultural background differs from the country they are settled in and whose first language differs from the dominant language of that country (Verdon et al, 2015).

1.2.3 Defining 'Newly arrived'

For the purposes of this thesis, 'newly arrived' describes families who have arrived in Australia in the last ten years. This includes both migrants (individuals who *voluntarily* left their country of origin, to permanently or temporarily live in a new country) and refugees (those forced to flee their country and seek refuge in a new country (UNHCR, 2019). The terms 'migrant' and 'refugee' are limited as they do not adequately capture all aspects of an individual's experience or identity, however, are incorporated under the phrase 'newly arrived' in this thesis for brevity (Due & Riggs, 2009; Due & Riggs, 2016).

This thesis will use the phrase "newly arrived CALD families" with an acknowledgement that the people included within this term are highly heterogenous.

1.3 ASD diagnosis and the role of language

Diagnosing ASD can be difficult as it relies on assessing behaviour and development in comparison to what is considered 'typical' (Wallis & Pinto-Martin, 2008). The diagnostic process also varies amongst individuals owing to the unpredictable presentation of symptoms (Matson & Sturmey, 2011). Commonly, ASD indicators are first noticed by parents, school staff or at regular developmental screenings such as those conducted in Australia (Department of Health and Ageing, 2011). Specific tests for ASD may then be conducted using developmental screening and diagnostic tools (Braiden, Bothwell, & Duffy, 2010; Noland & Gabriels, 2004; Whitehouse, Evans, Eapen, Prior, & Wray, 2017). After diagnosis, parents are typically directed towards speech and language therapy and social skills learning therapy. Early intervention for behaviour and development stands as one of the most successful avenues for ASD management (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Magan-Maganto et al, 2017; Paynter, Trembath, & Lane, 2018).

Atypical language development is often one of the first markers for diagnosis of ASD (Tryfon, Foster, Sharda, & Hyde, 2017). However, while previous versions of the DSM considered language impairment a central component, the current DSM-5 does not (5th ed.; DSM-5; American Psychiatric Association, 2013), primarily due to unpredictability in language and communication skills among individuals who meet other criteria for an ASD diagnosis (Kjelgaard & Tager-Flusber, 2001; Rogers, Naigles, 2017; Wittke, Mastergeorge, Ozonoff). While language is no longer considered important in the DSM in terms of diagnosis, this variability in language presentations is precisely why it is important to understand language and ASD in CALD populations. It is particularly important, when considering families that are receiving the diagnosis in a language other than their first language (Verdon et al, 2014; Verdon et al, 2015)

Research has consistently found that many children with ASD have greater challenges with both receptive and expressive language than typically developing children (Kwok, Brown, Smyth, & Cardy, 2014; Luyster, Lopez, & Lord, 2007; Ray-Subramanian & Weismer, 2012). Furthermore, studies suggest that children with ASD typically show greater impairment in receptive language than expressive language (Maljaars, Noens, Scholte, & Berckelaer-Onnes, 2012; Weismer, Lord, & Esler, 2010). Alternatively, research into language learning indicates that most people find understanding a new language (receptive) easier than producing it (expressive) (Hemsley, Holm, & Dodd, 2010). In the case of newly arrived CALD children with ASD, this may raise inconsistencies, with a diagnosis suggesting they are more likely to struggle with receptive language, however, acquiring English as a new language, suggesting expressive language may be more difficult (Hemsley et al, 2010). Evidently this is a contradiction that needs to be considered when assessing a CALD child for an ASD diagnosis.

Most research concerning CALD children with ASD focuses on family challenges around diagnosis and service access, or multilingualism. While a few studies suggest that speaking more than one language *may* be difficult for children with ASD (Bird, Lamond, & Holden, 2012; Yu, 2013; Ohashi et al, 2012), more recent literature suggests that multiple language exposure in children with ASD does not necessarily lead to any communication delays (Drysdale, van der Meer, & Kagohara, 2014; Gonzalez-Barrero & Nadig, 2018; Iarocci, Hutchison, & O'Toole, 2017; Kay-Raining Bird, Genesee, &Verhoeven, 2016; Uljarevic, Katsos, Hudry, & Gibson, 2016).

Most newly arrived CALD parents of children with ASD, are committed to ensuring their child learns the language of their home country, often indicating that it strengthens their connection with family and community (Hampton, Rabagliati, Sorace, & Fletcher-Watson, 2017; Jegatheesan, 2011). However, some parents report facing challenges with professionals who were unsupportive of their decision to maintain their native language in their home, while their child who has ASD, was learning a new one (Jegatheesan, 2011). Literature suggests that CALD children in general, face a lack of support (Mueller & Singer, 2006; Pieretti & Roseberry-Mckibbin, 2016) and that tensions exist between CALD families and professionals, however research into ASD within this context is scarce. These tensions are made more difficult because professionals may find it challenging to identify whether language discrepancies are due to a language difference or to a developmental disorder such as ASD (Burr, Haas, Ferriere, 2015). As such, students still learning English may be misidentified as presenting with traits relating to language disorders or ASD (Burr et al, 2015; Dennison, Hall, Leal, Madres, 2019). Conversely, some studies suggest that the apparent underrepresentation of ASD in ethnic minority groups (Beeger, Bouk, Boussaid, Terwogt, & Koot, 2009; Mandell et al, 2009) may result from unduly categorising language delays to language proficiency rather than ASD (Beeger et al,2009). Further evidence, that

the current ASD diagnosis process needs more attention for its applicability to newly arrived CALD children.

1.4 Community attitudes, culture, and ASD

A degree of stigma remains in perceptions of ASD within the general community (Kinnear, Link, Ballan, & Fischbach, 2016; Zuckerman et al, 2018), and diagnoses often result in stress for families (Gray, 2003; Myers, Mackintosh, & Goin-Kochel, 2009). Studies have reported that parents often feel invisible to society due to a lack of understanding and lack of recognition of their challenges (Woodgate, Ateah, & Secco, 2008).

Importantly, perceptions of ASD differ across cultures given their varying conceptualisations of health and illness (Mandell & Novak, 2005), including cultural understandings of mental health (Yang, Liu, Sullivan, & Pan, 2016). As such, how families perceive ASD and its associated behaviours in children, is influenced by their cultural background (Ennis-Cole, Durodoye, & Harris, 2013). Research indicates that because diagnosis is often based on social and behavioural elements, there will be diagnostic disparities, resulting from culturally different interpretations of behaviour (Perepa, 2014; Wilder et al, 2004). For example, some cultures consider direct eye contact disrespectful, however a lack of eye contact is a key consideration towards an ASD diagnosis (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Harrison, Long, Tommet, Jones, 2017; Wilder et al, 2004). Where ASD or a corresponding disorder *is* recognised, beliefs around causality may differ (Ennis-Cole et al, 2013). Similarly, how different cultures respond to ASD, in terms of interventions, also differs (Mandell & Novak, 2005), including perceptions of whether or not professional care is warranted (Kang-Yi, Grinker, & Mandell, 2013). Such perspectives must be identified and acknowledged, if a CALD child may be diagnosed with ASD in a culturally different country such as Australia.

1.5 Access to ASD Services

The ASD diagnostic process can be challenging for families (Mansell & Morris, 2004). In Australia, the diagnosis process can involve extensive waiting times (Crane, Chester, Goddard, Henry, & Hill, 2016; Oswald, Haworth, Mackenzie, & Willis, 2017), unless families can opt for private services which are more expensive (Shattuck & Grosse, 2007). More generally, international research has found that parents find the diagnosis process to be time consuming and strenuous (Crane et al, 2016; Oswald et al, 2017),). Parents also reported needing to advocate for their child in a system which does not meet their needs (Boshoff, Gibbs, Phillips, Wiles, Porter, 2016)

1.5.1 Access to Healthcare Services for Newly Arrived CALD Families

Resettlement poses numerous challenges to newly arrived CALD families, including finding housing, securing employment, language barriers, isolation and more (Abdelkerim & Grave, 2012; Agrawal, 2018; Lee, Sulaiman-Hill, & Thompson, 2013; Porter & Haslam, 2005; Santos & Webber, 2009). These challenges may be exacerbated when trying to access healthcare (Morantz, Rousseau, Banerji. Martin, & Heymann, 2013; Rousseau et al, 2008). Particularly, limited English language literacy, limited transport, and an unclear healthcare system have been identified as issues. (Sulaiman-Hill & Thompson, 2012). However, limited literature explores the challenges that newly arrived families experience, specifically relating to accessing ASD services (Graham et al, 2016), with most research focusing on ASD prevalence or risk factors in newly arrived families (Bolton et al, 2014; Graham et al, 2016; van der Ven et al, 2013). Those that do explore service access, suggest that more action is required for services to be better accessible, more beneficial and culturally appropriate for newly arrived CALD families (Fox et al, 2017; Walker-Dalhouse & Dalhouse, 2015).

Furthermore the research into ASD in CALD populations does not investigate the opinions of service providers, but almost exclusively focuses on service users and families. While service users provide a vital perspective, they can only speak to their own culture and experiences. Service providers, however, are exposed to varying clients and situations therefore adding more breadth to the research. Additionally, they work on the frontline of ASD, providing diagnoses and liaising with families, therefore their perspective is crucial. Studies investigating the barriers to healthcare for newly arrived CALD families, found that language and communication challenges effected every stage of general healthcare access (Chen, Garret, & Hillman, 2011; Morris, Popper, Rodwell, Brodine, & Brouwer, 2009). Many studies found that interpreters are a necessary tool that are not adequately utilised by healthcare systems (Gray et al, 2011; Henderson & Kendall, 2011).

Cultural sensitivity is another important element of healthcare access for newly arrived CALD families (Park, Chesla, Rehm, & Chun, 2011). This includes ensuring their cultural understandings of mental health and illness are taken into account at all stages of healthcare for CALD populations (Betancourt, Green, Carrillo, & Ananeh-firempong, 2003; Chang, Simon, & Dong, 2010; Crociata, Agovino, & Sacco, 2013; Grossi, Sacco, Blessi, & Cerutti, 2010; Saha, Beach, & Cooper, 2008). Cultural appropriateness is especially important for ASD services, because, as discussed in Section 1.4, benchmarks for social skills and behaviours, vary cross-culturally. (Perepa, 2014; Wilder et al, 2004).

1.6 Aims

Few studies have investigated ASD service access for newly arrived CALD families, and fewer still, focus on language specifically. Given this lack of research into diagnosis and service access for newly arrived CALD families, this research aimed to 1) explore perceptions of how ASD is perceived within CALD communities, and 2) explore barriers/facilitators in ASD diagnosis and service access, with a specific focus on language.

These aims are explored from the perspective of service providers, since, as noted previously, they offer a unique perspective that little research has utilised to date.

CHAPTER 2

Method

2.1 Participants

Participants consisted of 12 Melbourne based service providers with experience providing an ASD service, ranging between ten months and 23 years (M = 8, SD = 6). As shown in Table 1, this included seven Behavioural Therapists (of which two were male), three speech pathologists, one social worker and one teacher with Occupational therapy (OT) experience (all female).

Table 1

Participant characteristics (Service Providers)

Participant	Gender	Occupation	Years of Experience
[redacted]	Female	Behavioural Therapist	2
[redacted]	Female	Behavioural Therapist	8
[redacted]	Male	Behavioural Therapist	6
[redacted]	Female	Behavioural Therapist	3
[redacted]	Female	Speech Pathologist	12
[redacted]	Male	Behavioural Therapist	<1
[redacted]	Female	Behavioural Therapist	23
[redacted]	Female	Behavioural Therapist	7.5
[redacted]	Female	Speech Pathologist	7
[redacted]	Female	Social Worker	7
[redacted]	Female	Speech Pathologist	6
[redacted]	Female	Teacher/Occupational therapist	10

2.2 Procedure

The study was approved by the University of Adelaide Human Research Ethics Committee on April 18th, 2019 (approval number: [redacted]). The participant inclusion criteria requested service providers with ASD working experience, including both healthcare service

providers and school counsellors, in order to provide triangulation for the data (Braun & Clarke, 2013). Experience or knowledge of working with newly arrived CALD families was necessary, and all participants needed to be over the age of 18 and fluent in English.

Participants were recruited using flyers (See Appendices A and B) distributed on various social media platforms, and through professional contacts of primary researcher, Ravina Perera (RP) and Research supervisor Dr Clemence Due (CD), followed by passive snowball sampling. Seventeen healthcare organisations or individuals were contacted, including occupational therapists, speech pathologists, paediatricians, psychologists and Behavioural Therapists. Of these, four organisations responded and a further three agreed to distribute the flyer through their organisation. One of these organisations was an Behavioural Therapy clinic that the primary researcher RP had previously worked at.

Potential participants were invited to express their interest or queries by contacting the researchers via email or phone. After making contact with the researchers, they were emailed an official Participant Information Sheet (See Appendices C and D) followed by a consent form (See Appendices E and F) which they read, signed and returned if they wished to participate. The consent form indicated that participation was voluntary, that they were free to withdraw from the study at any time and asked whether they consented to be audio recorded. Verbal consent was also obtained at the start of each interview and recorded on the audio.

To recruit school counsellors, three private schools in the city centre were contacted via email, however no responses were received. An ethics application was also submitted to the Department of Education and Child Development. Approval was received on the 19th of August 2019, however by this time, data collection had ceased. As such, participants were all ASD service providers, as noted above in Section 2.1.

Interviews ran between June and August 2019, and were conducted via telephone, as all participants lived interstate. Interviews were audio recorded using a Smartphone voice recorder application. Interviews ranged between 31 and 59 minutes, with an average of 45 minutes. Interviews were conducted solely by the primary researcher, RP, excluding one interview that was conducted together with the research supervisor, CD.

The interview schedule was semi-structured with open ended questions (See Appendix G). Questions were constructed following careful consideration of the previous literature outlined in Chapter one specifically; Beeger et al. (2009), Dyches et al. (2004), Fox et al. (2017), Jegatheesan (2011), Mansell and Morris (2004), Norbury and Sparks (2013), Wallis and Pinto-Martin (2008). The first four demographic questions explored the participant's professional experience with ASD and newly arrived CALD families. Subsequently, ten open ended questions addressed the participant's experiences and opinions regarding ASD in newly arrived CALD families. Specifically, exploring participant's views on service access for newly arrived CALD families and the role of language through the ASD process.

Following Braun & Clarke's (2013) suggestions for ensuring strong and precise qualitative research, immediate post-interview reflections were made to observe for any necessary changes to the interview schedule. The schedule was reviewed following the fifth interview, in response to the participant's detailed discussion about her negative experience with an interpreter. Subsequent participants were often prompted on their experience working with interpreter services.

Interviews were transcribed verbatim by primary researcher RP, including all relevant verbal speech and utterances. To maintain confidentiality and anonymity, all participants received a pseudonym at transcription, and all identifying features were removed. Once

transcribed, recordings were copied onto a password protected computer and deleted from the recording device. Data saturation was achieved by the 12th interview (Braun, & Clarke, 2013) and no more interviews were conducted after this point.

Consistent with Tracy's (2010) "Big Tent" criteria for excellence in qualitative research, a self-critical audit trail was kept, to increase transparency of the methodological process. It included records of all email and social media correspondence with potential and actual participants, including the attempts at triangulation (school counsellors). All draft and final versions of the interview schedule were included, as was the entire process of data analysis and coding. Participants were offered the opportunity for member checking, should they wish to provide feedback or request modifications. Two participants accepted but didn't request any changes.

Lastly, self-reflexivity is important in qualitative research to consider any preconceptions, values and biases that may have influenced the study (Tracy, 2010). The primary researcher, RP is a young female who is neither diagnosed with ASD, nor has a family member diagnosed with ASD. This lack of personal experience may have led to oversights with creating questions and identifying themes. RP does, however, have two years working experience as a Behavioural Therapist for children with ASD, which may have allowed for simple and efficient communication with the service providers. Alternatively, personal opinions RP had formed through this work may have subconsciously steered the interview direction. By having parents of migrant background and often interacting with family and friends of migrant background, RP may have oriented to particular aspects of migration that influenced data analysis. Conversely, this connection may have allowed for an empathic, respectful and culturally sensitive approach to the research.

2.3 Data Analysis

Inductive thematic analysis was used to analyse the data. All analysis was dictated only by the content of the data and not by pre-existing concepts (Braun & Clarke, 2013). The data was analysed following six key phases as directed by Braun & Clarke (2013). The first phase was initial familiarization by completely immersing oneself in the data. This was achieved through transcriptions which were repeatedly read and annotated to note possibly important ideas. Secondly, initial codes were produced for all 12 interviews, then organized into mutual codes across all interviews. Thirdly, these were further collated to extract potential themes and corresponding subthemes, with all relevant extracts identified. Fourthly, these initial themes were compared to the full dataset and codes as well as their relevance to the study's aims. Fifthly, the most relevant themes, best capturing the data and the research questions, were refined and named. Finally, the most captivating extracts were drawn to represent the final themes and subthemes. The entire analysis process was periodically cross-checked by the academic supervisor CD, to ensure each stage and the resulting themes were consistent and trustworthy (Braun & Clarke, 2010).

CHAPTER 3

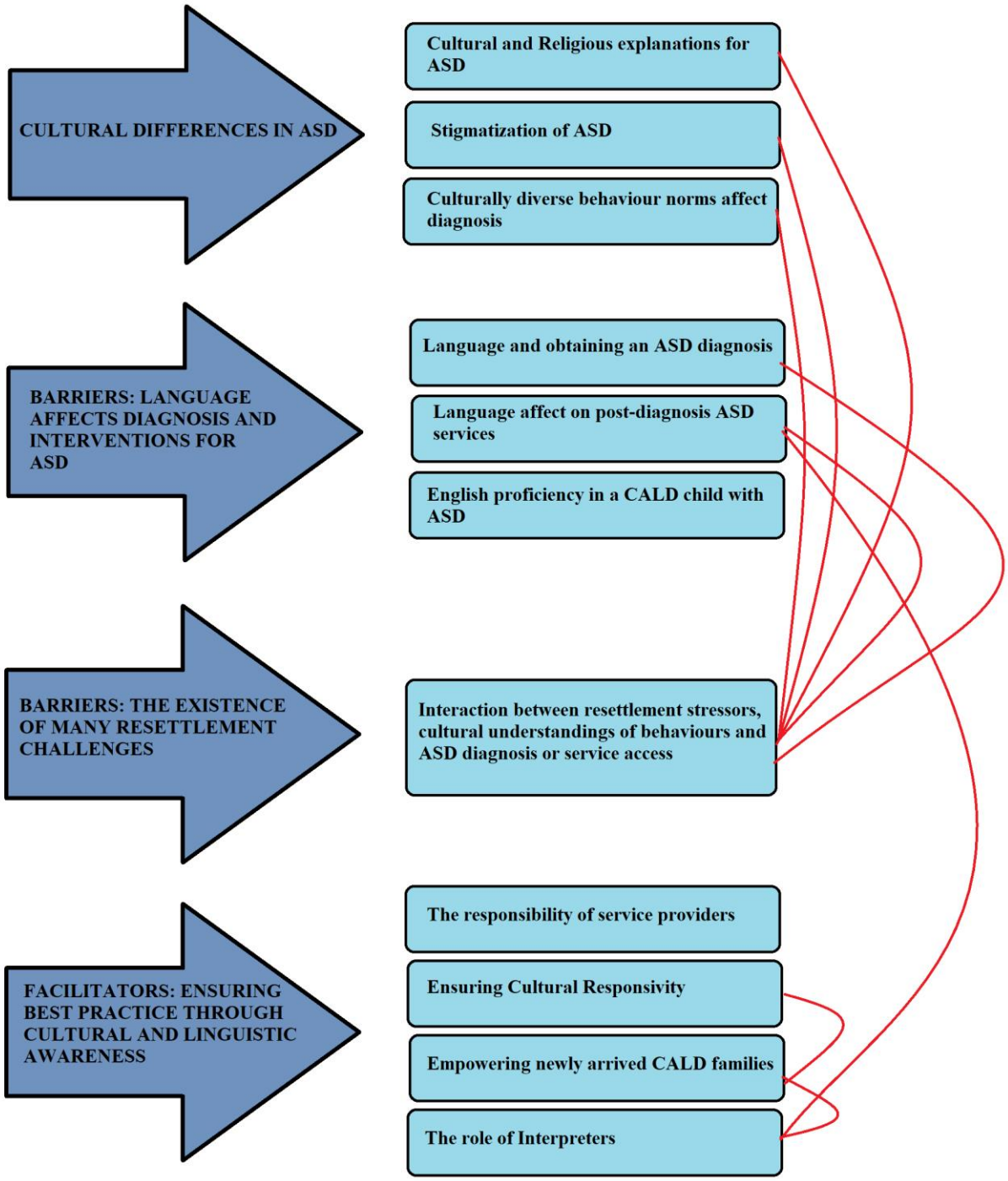
Results

3.1 Overview

The results are categorised into four major themes that were drawn from the data, that best answered the research questions. Section 3.2 explores cultural differences in ASD, section 3.3 explores how language affects diagnosis and interventions for ASD, 3.4 discusses the existence of many resettlements challenges effecting ASD. Finally, section 3.5 explores facilitators in ensuring best practice through cultural and linguistic awareness. Each of the four themes are often narrowed down to subthemes to highlight important aspects (see Figure 1 for a thematic map).

Figure 1

Thematic map



3.2 Cultural differences in ASD

As discussed in Chapter one the fact that ASD is a disorder primarily based on social determinants, means that different cultures have different understandings of the disorder and associated symptoms. Participants echoed this, noting that for many people with CALD backgrounds, ASD "doesn't even exist in their world" ([redacted] Behavioural Therapist, lines 353-354),

3.2.1 Cultural and religious explanations for ASD

Participants indicated that, where ASD was an unknown, newly arrived CALD families would try to "fit their understanding of what's happening to their child into what they already know" ([redacted] Speech Pathologist, lines 69-70). The influence of religious beliefs in particular was mentioned, as one example of how newly arrived CALD families informed their understanding of what caused ASD:

> "I've had some culturally diverse families who have had a different understanding of what might have caused Autism. Maybe even saying that this was gods will or um in terms of the way they understand disability; so more related to religion or customs in their culture."
>
> ([redacted] Speech Pathologist, lines 110 -112)

"God's will" as [redacted] mentions above, echoes a concept of punishment that was discussed by some participants. Specifically, [redacted] spoke about mothers who felt their child's diagnosis was the result of their actions and that God was possibly cursing them for what they had done in a previous life:

> "We've got [CALD] mums who truly completely and utterly believe that they've been cursed, that they did something wrong in a previous life and that's why they've been given a kid with Autism, or they may think it's their god that's cursing them because they did whatever"
>
> ([redacted] Behavioural Therapist, lines 75-77)

Similarly, the general concept of blame was discussed. Not only did participants feel that parents blamed themselves for the diagnosis, due actions in their past life, as mentioned above by [redacted] but also due to their actions during pregnancy or when parenting:

> "Different cultures have different beliefs around what causes Autism. Some communities are still believing that parenting practices can cause Autism and think that what the mother does in pregnancy, or neglecting the child, can be a cause of Autism. I find those families are less accepting and more um try to decrease the behaviours as quickly as possible or hide the behaviours…rather than trying to understand them. I guess they just want them to stop"
>
> ([redacted] Behavioural Therapist, lines 64-69)

Here, [redacted] connects families that attribute blame to themselves, as less accepting of the diagnosis and more likely to conceal it. This idea of hiding ASD relates to some aspects of social isolation which will be discussed further in section 3.4.1 that looks at resettlement challenges. While participants often spoke of blame in newly arrived CALD families, they also acknowledged that this perspective wasn't unique to CALD populations. Participants stated that blaming one's self for the diagnosis was evident in Australian families as well, however said it may play a bigger role for newly arrived CALD families:

> "I think also this [blame] isn't just related to varied cultures. I see it with my Australian families as well, but maybe particularly more for some cultures- that blaming on the parents, there's the view that if your child's having difficulty it's your fault and you should have been a better parent"
>
> ([redacted] Speech Pathologist, lines 106-109)

3.2.2 Stigmatization of ASD

Given some of these negative associations often made with an ASD diagnosis, participants further discussed the existence of stigma surrounding ASD. However, just as the

concept of 'blame' wasn't necessarily unique to CALD families, participants also agreed that stigmatization of ASD was apparent in all cultures:

> "It is always going to have this stigma around it, and that is cultural, depending on what culture you come from. Western culture has that stigma around it and culturally diverse people have a stigma around it as well"
>
> ([redacted] Speech Pathologist, lines 214-217)

Nevertheless, as [redacted] (above) suggests, stigma was seen as culturally dependant. So while participants agreed that stigma existed regardless of culture, they also said that "in one culture there might be a significant stigma and in another not so much" ([redacted] Behavioural Therapist, line 63). Furthermore, participants said that newly arrived CALD families from cultures with higher levels of stigma, may react in ways indicative of how the disorder was perceived in their home country. For example, participants said that some newly arrived CALD families were "very keen to keep the diagnosis secret" ([redacted] Behavioural Therapist, lines 62-63). Furthermore, Bella stated that the way in which disability in general is handled in their home country may lead to assumptions of how their child may be received in Australia:

> "Probably from the way kids with disability back in their home countries are segregated, I think they'd [CALD parents] just naturally assume their child has to be segregated because they have a disability"
>
> ([redacted] Behavioural Therapist, lines 286-289)

3.2.3 Culturally diverse behaviour norms affect diagnosis

Participants acknowledged that diagnosing for ASD was difficult due to its reliance on behaviour and developmental standards. They said that these standards varied cross-

culturally and an ASD diagnosis wasn't as straight forward as a quick medical test such as a blood test:

> "You can't just you know, take a blood test and then be confirmed if you have Autism or not, because it's based on all this behaviour, communication and developmental standards, and because all that stuff differs from culture to culture it can be tricky to translate"
>
> ([redacted] Behavioural Therapist, lines 399-402)

[redacted] spoke extensively of this aspect of diagnosing ASD, highlighting an example that "a typical sign in a Western, Australian English-speaking household, of an ASD diagnosis, is an absence of eye contact…but in some cultures, not making eye contact is the cultural standard". His idea was supported by [redacted] who mentioned several other expectations of an ASD diagnosis that varied between cultures, suggesting that it made the diagnostic process complex and ambiguous:

> "You know things like eye contact, things like how you interact with strangers, appropriate responses to someone having a birthday party…you know all of those things can look different in different cultures so um yeah that makes [diagnosis] trickier, adds extra layer of complexity or ambiguity"
>
> ([redacted] Speech Pathologist, lines 232-235)

Participants suggested that this disparity and its effect on a diagnosis needed more consideration. [redacted] specifically stated that the complexities arising from these cross-cultural differences needed more care and attention than it currently received:

> "So you've got to be really careful of what is a child deficit and what is just a cultural difference, um and I don't think that that comes up enough in the diagnosis component of it"
>
> ([redacted] Behavioural Therapist, lines 271-273)

3.3 Barriers: Language affects diagnosis and interventions for ASD

The effect of language on an ASD diagnosis and service access, was a key focus of this research, and extensively discussed by participants. Whether they spoke about pre-diagnosis or post-diagnosis, the general consensus was, that the "English language barrier was that key gate keeper out of services because you don't even know how to go and get the information" ([redacted] Speech Pathologist, lines 297-298).

3.3.1 Language and obtaining an ASD diagnosis

As discussed in Chapter One, the process for obtaining a diagnosis can be lengthy, and often begins with a GP or paediatrician in Australia. Participants spoke of this process and suggested that for newly arrived CALD families with a lack of English proficiency, the process would be difficult. [redacted] (below) suggested that the level of services necessary prior to receiving diagnosis is overwhelming, particularly if you don't speak English:

> "Oh it's such a run around to work around how to get your kids the right service and you know if you need to see a paediatrician to get that referral, and then if you have private health cover or is that covered by Medicare or is that an out of pocket expense, all that kind of stuff, particularly when you're on a very low income if any income at all, and you've got a hundred other things that are on your plate, and you don't speak English so you can't just google it, I know some things are available online in translations and things like that, but it's still not straight forward"
>
> ([redacted] Speech Pathologist, lines 278-284)

[redacted] also mentions the effect of a low income, which is an idea that is mentioned again in section 3.4, as it looks at resettlement challenges faced by newly arrived CALD families. Interpreters were mentioned as vital in assisting newly arrived CALD families navigate the linguistic barriers of accessing services. Participants state that much of their work liaising with newly arrived CALD families "can't be done without an interpreter" ([redacted] Speech

Pathologist, lines 146-147) however participant [redacted] (below) also mentioned that even accessing interpreters requires some level of English:

> "people often say 'oh yeah we have interpreters' but how do you even get an appointment to get in and get an interpreter, you know so there's that gate keeping that goes on if you just don't know how to read pamphlets"
>
> ([redacted] Speech Pathologist, lines 298-300)

The role of interpreters will be discussed further in section 3.5.4.

Participants asserted that even once newly arrived CALD families had found a service provider to diagnose their child, further linguistic challenges arose. The language associated with an ASD diagnosis was said to not "translate well at all [and be] quite jargon-y. The criteria and what [it] means…[was] really hard to understand" ([redacted] Behavioural Therapist, lines 150-152). This technical language alongside a language barrier made providing a diagnosis difficult as it was impossible to know how much the families understood:

> "Whether a client has understood what I'm saying, because I don't know, I can't understand what the interpreter has said, so it's difficult for me to know whether they've conveyed it accurately, and whether the family has understood."
>
> ([redacted] Speech Pathologist, lines 264-269)

As [redacted] mentions above, this difficulty was even present when using an interpreter, as she was unable to monitor what was being said by the interpreter and whether it was correct and understood. Furthermore, the language barrier at diagnosis, was said to possibly hinder a CALD parent's ability to voice their own concerns:

> "A complete language barrier too. It's not just receptively understanding the diagnosis, but for a family to be able to explain their concerns, like having the language to say, you know 'I'm concerned because x, y, z'"

([redacted] Behavioural Therapist, lines 149-152)

As such, without the language to do so, newly arrived CALD families are not able to play an active role in the exchange. Overall, participants agreed that newly arrived CALD families experience many challenges as early as diagnosis, and that "language would be a huge barrier in terms of understanding the full scope of a diagnosis" ([redacted] Behavioural Therapist, lines 92-93).

3.3.2 Language effects on post-diagnosis ASD services

Just as it existed at diagnosis, the language barrier was raised as challenging throughout post-diagnosis services such as therapy for ASD. Often participants reported that they required clear descriptions of a child's behaviour and routines at home. However they said newly arrived CALD families struggled linguistically to relay all important information:

> "It's been really hard to work out exactly where they [CALD parents] are at, as well as obviously, communicating things about; what's going on at home, how often particular behaviours happen, what we want, what we're recommending that they do with their son or daughter at home – can be really tricky"
>
> ([redacted] Behavioural Therapist, lines 262-265)

As [redacted] mentions above, participants indicated that it was difficult to communicate what actions were recommended for within the home. Furthermore, participants specified that it was unclear whether these suggested interventions, if understood, were actually implemented at home, a lack of which could be detrimental to the child:

> "If communication is not there across any kind of intervention or therapy or support, then if you're not able to effectively communicate what's happening and when things aren't being followed through outside of sessions, it means that outcomes will be less or lower [for the child]"

([redacted] Teacher/OT, lines 256-258)

Moreover, discussions around the interventions themselves, were considered problematic, as parents may not be accurately informed of the therapy their child was undergoing. [redacted] suggested that this made it difficult to gauge whether informed consent was actually given by parents to employ strategies:

> "It's also hard sometimes to work out um to what level the consent is there, even from the parents. Like if you decide that you're going to work through something like; the kid might be picking at the skin of their fingers or something, and we've decided it should be worked through. Sometimes it's hard when you've got a language barrier to read whether the parents truly consent to what you're recommending, or whether they just don't understand you properly"
>
> ([redacted] Behavioural Therapist, lines 168-172)

As such, the necessary informed collaboration throughout therapy is not possible due to an inability to facilitate efficient conversation between service providers and newly arrived CALD families.

3.3.3 English proficiency in a CALD child with ASD

The English proficiency of a CALD child diagnosed with ASD raised several concerns reported by the participants. Firstly, at diagnosis, participants suggested that, as with any language-based disorder, "it's always a huge question of; 'Is this actually a language disorder or is it a language difference?'" ([redacted] lines 220-221). They highlighted that the standard expectancy of English language within therapy in Australia wasn't appropriate for a newly arrived CALD child:

> "They've [CALD children] been exposed to English less, their Receptive and Expressive language delays might not be solely from the Autism diagnosis. It might also just be due to a lack of practice compared to someone that's grown up in an English-speaking household"
>
> ([redacted] Behavioural Therapist, lines 353-356)

Participants stated that it was not possible to claim that a newly arrived CALD child's linguistic challenges resulted from an ASD diagnosis. Moreover, using English to assess for ASD in a CALD child, was thought to fuel these confusions around 'language difference' or 'language disorder':

> "If you're only testing in English, and English is their [CALD child's] second language, then that's going to mask whether it's an exposure to English issue or whether it's an actual delay or disorder, because they could have really poor English skills just because they haven't heard much English. So unless you're assessing in the first language you're never going to know"
>
> ([redacted] Speech Pathologist, lines 138-142)

As such, suggestions were made that the current method for assessing for ASD, wasn't appropriate for a CALD child, particularly if they were newly arrived in Australia. In fact, [redacted] (below) went on to say that the current practice was highly unethical when used with CALD children, as it didn't adequately incorporate the specific child's language. She highlighted the importance of using more appropriate assessments and interpreters to efficiently identify the child's needs and provide assistance:

> "Practice is so unethical and inappropriate for these [CALD] kids, and the amount of hours that are wasted, that could be used doing a dynamic assessment or working with interpreters, to try and find out exactly where the kids are with their language, and what you could actually do to functionally help them get through their day"
>
> ([redacted] Speech Pathologist lines 127-130)

Once such a diagnosis is made, challenges around a child's linguistic diversity were reported as also existing in therapy. Specifically, the Behavioural Therapist participants said that their language difference with their client made it impossible to reinforce correct communications. [redacted] (below), outlined how a therapist's lack of knowledge of the client's language, led to missed opportunities in honouring communication:

> "It's very difficult to reinforce a child who's using another language to communicate…So an example could be if they're playing with a doll house, and they might have a baby, put the baby in the bed, and they might say 'sleep' in another language, and we don't know so we can't then connect and say 'YAY SLEEP' or repeat it back because we don't know"
>
> ([redacted] Behavioural Therapist, lines 162-168)

A similar idea was conveyed about a child requesting, for example "to go to the toilet in Hindi or whatever – not English" ([redacted] line 180). Participants suggested that failing to honour such requests may hurt a child's progress because "there's often a bit of shut down, and then they'll stop trying to use it" ([redacted] Behavioural Therapist, lines 159-160). In general, participants asserted that language barriers weren't considered enough in services, and that "we have a very monolingual mindset when it comes to healthcare practice in this country" ([redacted] Speech Pathologist, lines 407-408).

3.4 Barriers: The existence of many resettlement challenges

Participants indicated that, in addition to language, other resettlement challenges also posed an issue for ASD diagnosis and service delivery with newly arrived CALD children. Often newly arrived CALD families are yet "to find housing…get schooling and find employment" ([redacted] Speech Pathologist, lines 306-307) and "on a very low income if any income at all" ([redacted] lines 281-282). A subtheme was identified in the interaction these challenges had with cultural understandings of behaviour and ASD diagnosis and service access, as discuss below.

3.4.1 Interaction between resettlement stressors, cultural understanding of behaviours and ASD diagnosis or service access

Participants indicated that in light of the challenges mentioned above (section 3.4), seeking ASD services may be difficult. Whether an ASD diagnosis was prioritised above these challenges was said to depend on how settled newly arrived CALD families were in their new country:

> "If you haven't found a proper place to live, you haven't got employment yet, and you're dealing with all of those resettlement challenges, I would say getting a diagnosis could then sort of fall under the radar a little bit, because you got all these pressing immediate challenges that you have to deal with, in order to survive. Like actually find a place where you would then go out and seek intervention"
>
> ([redacted] Behavioural Therapist, lines 216-220)

As such, seeking a diagnosis may not be considered a high priority if their basic needs are not met. This was also said to occur when accessing ASD interventions, that even after diagnosis, the subsequent steps may not take place if newly arrived CALD families are not completely settled:

> "It's really difficult to look at those higher-level needs when you don't have your basic needs met. Often newly arrived…populations are very much in crisis mode so it's much harder to think productively about your child and their education and developmental needs when you're in crisis mode and you're so traumatized yourself. But having said I've absolutely worked with families who have a million other things happening, but they really make their child's therapy and their child's development their absolute priority"
>
> ([redacted] Speech Pathologist, lines 174-180)

As such, if newly arrived CALD families are in 'crisis mode' they may not seek an ASD diagnosis, however participants also suggested that this may depend on the level of concern parents have over their child's behaviours. Participant [redacted] (below) suggested that if ASD symptoms presented more "severe", the necessity to seek services may prioritise higher:

> "How severe the difficulties are with the child – so if they're not even able to function with the child or they don't know how to help them with their daily activities, then I think that would make it a higher priority"
>
> ([redacted] Speech Pathologist, lines 273-275)

The specific resettlement challenges that newly arrived CALD families face, were said to also impact an ASD diagnosis. Participants indicated that there was considerable social isolation in resettling. They mentioned that this isolation may influence a family's ability to understand an ASD diagnosis, as they may be less exposed to it:

> "A lot of the culturally diverse clients that I've worked with are often quite isolated here in Melbourne, not all of them, some of them are part of a community, but a lot of the ones who are very isolated, I think might have more difficulty understanding Autism just because they haven't necessarily seen others with it"
>
> ([redacted] Speech Pathologist, lines 95-98)

Furthermore, participants suggested that this social isolation may increase challenges with service access as having a support network would make navigating the available services easier. They suggested that "you turn to your community, if you need help, if you don't know where to go" ([redacted] Behavioural Therapist, lines 97-98). [redacted] (below) further suggested that newly arrived CALD families would benefit from having an Australian support person, well versed in the system:

> "Unless you have an advocate or a support person, you know, an Australian support person who knows the system, to say; 'okay you got to call this person, go to this appointment, this is how much it's gonna cost, then go to this person and they'll give you a diagnosis', unless you have that kind of liaison person to explain the process I don't see how you ever navigate it"
>
> ([redacted] Speech Pathologist, lines 284-288)

[redacted] point (above) regarding a 'liaison' to navigate the services suggests someone who acts as a bridge between newly arrived CALD families and services. Such a concept is further explored in section 3.5.1 regarding best practice for newly arrived CALD families.

3.5 Facilitators: Ensuring best practice through cultural and linguistic awareness

3.5.1 The responsibility of service providers

Participants agreed that the responsibility of facilitating newly arrived CALD family's ASD journeys, lay primarily with service providers. They suggested that the process can be especially strenuous if families aren't initially given adequate information. This preliminary step was required to establish a good foundation:

> "Service providers can be a barrier or a facilitator as well. If a service provider doesn't meet the individual needs of that family or child, if they don't get the right thing straight away, that could be really challenging for families, especially, again, when they're not really sure what's happening"
>
> ([redacted] Teacher/OT, lines 175-180)

As briefly mentioned in section 3.4.1, navigating services can be overwhelming and confusing for newly arrived CALD families and a liaison was reported as necessary to bridge between the services. Participants indicated that service providers should be responsible for supplying these connections and that they should help families realise what services they require and attempt to facilitate those:

> "Engage with them [CALD families] and find out what they need, what other services they might need. Because ASD is not the type of condition where you just need a speech pathologist for example. You're going to need lots of other services, so you need to kind of be a bridge for the family"
>
> ([redacted] Speech Pathologist, lines 319-322)

Such a role was described by [redacted] who detailed her experience in social work, as someone providing support and information for families. She highlighted the benefits of this role and its ability to decrease confusion and consolidate information being received from multiple services:

> "I think one of the key things really during that key worker [Person who works as a general guide for families] role was to build up the relationship with the family from an early point. I worked in early intervention, with 0 to 6 years of age, so by coming in early as the key worker and building up a relationship with the family, they trusted me. It made it a much easier and seamless process to bring other workers in. So speechies, and OT's come in to support the child in their home environment and then once they have finished…I was there with the …and I would continue to work with the family and re-give the same information"
>
> ([redacted] Social Worker, lines 119-126)

3.5.2 Ensuring Cultural Responsivity

Participants suggested that ensuring their service was culturally responsive, was also the service provider's responsibility. [redacted] (below) stated that many newly arrived CALD families were vulnerable and faced many challenges (possibly referring to the resettlement challenges mentioned in section 3.4). To not increase these difficulties, [redacted] highlights the importance of ensuring an ethical and culturally responsive service:

> "It's that cultural responsivity, you know, the owners[hip] has to be on us as professionals because the families already have a lot of vulnerability, they already have a lot on their plate.

> We are delivering a service, and we have to make sure that that service is ethical and culturally responsive"
>
> ([redacted] Speech Pathologist, lines 333-336)

To accomplish this, participants emphasized that "training for staff is a huge part of that cultural sensitivity…and understanding around CALD family groups" ([redacted] Behavioural Therapist, lines 186-188). Participants often raised a desire themselves, to receive more training and workshops in providing culturally appropriate services for newly arrived CALD families:

> "It's something that needs to be delivered to clinicians, you know workshops about, you know, in the Sudanese community or in the Syrian community, how is ASD actually understood? And is it understood? …Yeah I think that would be really helpful"
>
> ([redacted] Speech Pathologist, lines 269-273)

The necessity for more training was raised often and participant [redacted] (below) claimed that this training was vital early in professional education, and required a greater portion the curriculum than it currently received:

> "In undergraduate, Master's degrees, an educational conversation around it [working with CALD clients]. I'm a very big advocate, at least in my course, that it's not a tack on. That we don't say; 'here's what we do for monolingual kids', and five minutes at the end of the course, say; "by the way, if they're multilingual this is what you should do too.' It has to be embedded"
>
> ([redacted] Speech Pathologist, lines 445-448)

While training for service providers was highlighted as important, participants also emphasized the value in diversifying staff. They indicated that incorporating service providers with a lived experience, from varying cultural backgrounds, was beneficial.

Participants declared that "the problem with creating support networks for people with diverse backgrounds, by people without diverse backgrounds, can be a huge barrier because you don't think about all those cultural norms". ([redacted] Teacher/OT, lines 232-234)

Additionally, to increase cultural responsivity, service providers were advised to actively open a conversation around culture and provide clients with the platform to voice their culturally influenced needs. Again, the responsibility was directed towards the professional, to ask necessary questions and avoid any stereotyping and assumptions:

> "I'm trying to get better at asking those questions myself just in terms of asking, "how is something like this seen in your culture?" or "how does your culture view children and raising children?" cos I try to be very mindful too of not making presumptions and stereotypes so understanding that everyone interprets their culture differently so trying to make it more specific to the individual rather than the culture that they're from if that makes sense."
>
> ([redacted] Speech Pathologist, lines 124-129)

Furthermore, some participants, particular those discussing therapy, reported instances where their program was adapted to incorporate the views of CALD clients. If say "its culturally inappropriate for adults to touch a child below the shoulders or something" ([redacted] Behavioural Therapist, line 198), they would adapt. Such accommodations could be made if newly arrived CALD families are able to voice their requests. However, as discussed in section 3.3.2, participants often said that understanding what culturally influenced requests existed, was difficult due to the language barrier. As such, interpreters were cited as an important tool in providing a culturally responsive service, which will be discussed in section 3.5.4.

3.5.3 Empowering newly arrived CALD families

The necessity to empower newly arrived CALD families was discussed as a way of providing parents with control over their situation. That newly arrived CALD families should be given the reigns in their child's ASD journey, rather than being told what is best for their child. Similar to the idea mentioned in section 3.5.2, service providers were advised to let the families communicate their view first, as they know their child best:

> "Putting parents in the pilot seat as they know their child best. So instead of coming in and telling the parents, we're just showing an interest and respecting. Find out all the information about the child to begin with"
>
> ([redacted] Social Worker, lines 179-181)

Likewise, participants insisted that a parent's ability to advocate for their child was a fundamental component of feeling empowered. For newly arrived CALD families "there's still very much a need…to be able to advocate really strongly for their child, but sometimes that's very difficult for migrants and refugees to do" ([redacted] Speech Pathologist, lines 190-191). [redacted] (below) suggested that to advocate for their child, newly arrived CALD parents needed to feel emotionally safe liaising with service providers. Such emotional safety may lead to stronger feelings of empowerment and better ability to advocate for their child. Services were again seen as vital in facilitating this by providing an accepting and inclusive environment:

> "Getting back to feeling culturally safe and emotionally safe, where you feel accepted, I think there's many kind of gestures and protocols that the centre can take to be inclusive and to make the families to feel safe when they're sharing such sensitive information about their home life and about their child"
>
> ([redacted] Behavioural Therapist, lines 200-203)

3.5.4 The role of interpreters

The empowerment of families as highlighted in section 3.5.3, was seen as achievable significantly through the use of interpreters. As discussed in section 3.3, language was considered a significant gatekeeper in all aspects of the ASD process. However using an interpreter provided families with the ability to communicate seamlessly and therefore gave them back control. This control was seen to help shift the power dynamic that existed between service provider and user to better suit the families:

> "It's about shifting that power dynamic and that's what interpreters are really good at. They fight a power dynamic, from someone being disempowered, to being empowered to actually speak what they want. Because it's very difficult to speak your mind, particularly if they're in an emotional state, if you trying to filter it through their second language"
>
> ([redacted] Speech Pathologist, lines 382-386)

Being able to 'speak your mind' as [redacted] mentions above, was considered one of the biggest benefits of utilizing an interpreter. Participants suggested that the presence of interpreters allowed newly arrived CALD families to control the pace and direction of the situation, and voice necessary questions. The inability to do so was also discussed earlier in section 3.3 as a result of the language barrier.

Participants often agreed that the current use of interpreters was lacking. Service providers were advised to always utilize interpreters where possible, and organise them proactively, if a need was identified. Such practices were seen as vital to ensuring the cultural responsivity that was discussed in section 3.5.2.

> "It [organising interpreters] has to be at that first enrolment stage, when you first come into the services, not when they come into your office…Someone needs to have worked that out earlier when they're taking the very first enrolment on the case load. To go; 'okay we need someone present, we need to pre-book them, we need to have them here. So it's that cultural responsivity"

([redacted] Speech Pathologist, lines 329-333)

Conversely, interpreters while vital, were also seen as having the potential to be counterproductive if they weren't "appropriately trained interpreters - that would make it difficult to deliver a culturally appropriate service" ([redacted] Speech Pathologist, lines 250-251).

CHAPTER 4

Discussion

4.1 Overview

This study used thematic analysis to explore ASD in newly arrived CALD families, and to identify the barriers and facilitators they face in obtaining a diagnosis and accessing necessary services. It focused specifically on the role of language and how a lack of proficiency in the language of their host country may influence their ASD experience. The identified themes explored four major facets of the ASD journey for newly arrived CALD families. Particularly interesting results within all four overarching themes will be discussed, along with the broader implications of this study in research and ASD practice.

Participants typically stated that perceptions of ASD varied among different cultures and agreed with past literature, that some cultures had no concept of ASD (Fox et al, 2017). They, like previous research (Ennis-Cole et al, 2013; Perepa, 2014; Wilder et al, 2004;) acknowledged that certain behaviours, commonly attributed to ASD, may be perceived differently in certain cultures. Like Dyches et al. (2004), Harrison et al. (2017) and Wilder et al. (2004), participants agreed that a behaviour such as lacking eye contact, while considered possibly indicative of ASD, may be considered the norm, or even preferred, in some cultures.

The findings also supported past literature in suggesting that stigmatisation of ASD exists to varying degrees in different cultures (Obeid et al, 2015). While this contributes to the literature it doesn't stand out as novel idea. Participants' also claimed that the attitudes of their home country may lead newly arrived CALD families, to assume they will receive similar judgement in Australia. Some studies have implied this by exploring mental health stigma within CALD communities (Nadeem et al, 2007; O'Mahony & Donnelly, 2007). However none specifically evaluate the idea that newly arrived CALD families may expect

and fear judgement in their new country due to this stigma, rather than simply having a stigmatizing attitude themselves, towards mental health. This could be an interesting avenue for future research, possibly amongst literature suggesting that some CALD individuals are less likely to access general health care services (Caperchione, Kolt, Tennent, & Mummery, 2011).

The study found that linguistic diversity was a barrier at every stage of ASD service access, as it did every stage of general healthcare access according to the previous literature (Chen et al, 2011; Morris et al, 2009). Findings indicated that to even be considered for a diagnosis, families needed a significant level of English proficiency to navigate the system and contact a professional to assess their child. While such findings mirror past research on resettlement challenges, (Chen et al, 2011; Morris et al, 2009), it assumes that these CALD families have concerns regarding their child's behaviour and development. This may not necessarily be the case in light of the varying cultural behaviour norms discussed earlier and seen in the literature (Daley, 2002; Matson et al, 2011; Matson et al, 2017; Perepa, 2014).

Conversely findings showed that upon receiving a diagnosis, families may struggle to understand what the diagnosis meant, due to an inability to understand the language and communicate queries. This supports past research into how CALD families experience receiving general diagnosis (Harry, 2008; Surbone, 2008) as well as few studies exploring this in the context of ASD (Jegatheesan, 2009; Jegatheesan, Fowler, & Miller, 2010). As such, if a CALD family received a diagnosis they didn't seek themselves (possibly visiting a GP for another condition), it could be argued that they lacked the English skills to convey that they didn't perceive their child's behaviour as problematic. This is an interesting avenue for future research to explore.

Participants often spoke of difficulties the language barrier posed when informing parents of details of therapy. Aside from the general acknowledgements of challenges due to linguistic difference in healthcare practice (Sulaiman-Hill & Thompson, 2012), past literature doesn't specifically focus on ASD therapy and liaising with families not fluent in English. The idea that some newly arrived CALD parents may not understand the service provider's desires for therapy, correlated with another finding relating to informed consent. While some research has investigated the difficulties in obtaining informed consent from a linguistically diverse client (Hunt & Voogd, 2007; Lee et al, 2017; Schenker, Wang, Selig, Ng, & Fernandez, 2007), few have explored it within ASD. This finding suggested that family's may not have a thorough understanding of the components of their child's therapy that they agree to. While some may argue, that a family that's at the point of receiving therapy, may have sufficient understanding of the diagnosis, when considering the significant impact of language, as found in this study and past literature, the possibility of misunderstandings through the diagnoses is high, (Jegatheesan, 2009; Jegatheesan, Fowler, & Miller, 2010). The effect of language on informed consent is not covered in past literature in regard to ASD, and future research should endeavour to explore this.

The study found that often a child's English proficiency wasn't accounted for in an ASD diagnosis, which may possibly lead to misdiagnosis, an outcome emulating past literature (Burr et al, 2015; Dennison et al, 2019). Results suggested that both receptive and expressive delays of a CALD child, may not be due to ASD, despite such delays indicating a diagnosis (5^{th} ed.; DSM-5; American Psychiatric Association, 2013). Further explorations of receptive and expressive language were not apparent in the findings however possible explanations for this are discussed in section 4.3. Service providers agreed that there was an obvious gap in understanding the specific needs of linguistically diverse children, not only at diagnosis but also during therapy. The latter is not as thoroughly investigated in the literature.

This study found that often, an inability to understand CALD clients and vice versa may lead to detrimental effects on their progress. This raises the question however, of why it is vital that therapies and general ASD services are delivered in English. A question that future research should investigate, possibly in relation to ABA therapy, as it is one of the only evidenced based therapies for ASD (Foxx, 2008).

Much of the findings relating to resettlement challenges mirrored previous research observing resettlement barriers for general healthcare (Morantz et al, 2013; Rousseau et al, 2008). Social isolation, which again, previous literature has discussed (Davidson et al, 2004; Porter & Haslam, 2005) was highlighted as relating to less exposure to ASD. Participants also suggested that resettlement challenges may force seeking an ASD diagnosis lower on the list of priorities. While this is a logical conclusion, it again assumes that CALD families see the ASD behaviours as atypical and does not consider that perhaps newly arrived CALD families are able to prioritise their resettlement, because they have no concerns regarding their child's behaviour. Since, as mentioned prior, literature agrees that some cultures do not perceive all behaviours associated with ASD as atypical (Daley, 2002; Matson et al, 2011; Matson et al, 2017) Furthermore, if a CALD family does obtain a diagnosis, participants indicated that perhaps their ability to respond to the diagnosis may be affected by their resettlement challenges. However, as previous research (DSM-5; American Psychiatric Association, 2013; Huerta & Lord, 2012; Matson & Sturmey, 2011) has depicted, ASD presents differently in different children, so, as this study's findings indicate, the level of 'severity' of symptoms may influence a family's haste to seek services. Nonetheless, family's perceptions of 'a severe presentation of behaviours' may differ, depending on their cultural understandings. This may reflect past literature looking at how different cultures view heath and illness in general (Mandell, & Novak, 2005). It also supports the literature suggesting that some cultures may not view mental health illness in the same way as Western Cultures (Karasz,

2005). More specifically, as mentioned earlier, it supports the literature indicating that, what behaviours CALD communities consider “atypical” or “severe” will vary cross-culturally (Matson et al, 2011; Matson et al, 2017; Perepa, 2014)

The findings suggest that being able to empower families and allowing them to advocate for their child are key components in providing a culturally appropriate service. The importance of advocacy in particular is supported through the literature exploring ASD parents in general (Boshoff et al, 2016; Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Interestingly, if, as the findings suggest, advocacy is an important right of any parent, surely a CALD parent’s right to advocate on behalf their child and potentially even declare that their behaviours are not atypical in their culture, is just as important.

The value of cultural responsivity in services is supported in previous research on working with CALD families (Park et al, 2011; Perepa, 2014; Wilder et al, 2004). A unique perspective found in this study was that cultural responsivity (all aspects of service facilitation in fact) was considered primarily the responsibility of the service provider. This is important when considering the comments about a lack of power and need for advocacy in CALD families. While service providers should take ownership in easing the ASD process, perhaps they should be mindful of not taking away any more power from these newly arrived CALD families.

The proposal that service providers may benefit from more culturally appropriate training, supports previous literature (Banerjee & Luckner, 2014). Alternatively, the results also highlighted the benefit of incorporating a single individual to work with newly arrived CALD families, acting as a bridge between services. Further investigations into this concept may assist in understanding whether a culturally and linguistically trained individual, familiar

with ASD, may ease the stress newly arrived CALD families feel when navigating available services.

The findings further reflect the literature (Gray, Hilder, & Donaldson, 2011; Henderson & Kendall, 2011) in that interpreters are vital in bridging the language gap but not adequately utilised in current healthcare. Furthermore, the findings supported research into newly arrived CALD families that found significant challenges in attempting to access interpreters (Dubus & LeBeouf, 2019; Hadziabdic et al, 2009). The idea that perhaps interpreters required better training to be as beneficial as possible was also found in Riggs et al. (2014). A fairly unique finding of the present study explored the importance of empowering families as a tool for facilitating their ASD journey. Although the finding of interpreters as a tool for empowerment was supported in past literature regarding general interpreter services (Hsieh, 2008) few explored the concept of empowerment alone.

In general, participants seemed to describe ASD as a universal concept, rather than possibly being just one western conceptualisation, of a certain set of behaviours. Their descriptions outlined the diagnosis as something newly arrived CALD families must inevitably accept, rather than simply being one culture's explanation for their child's behaviour. This is perhaps indicative of a need to change the way "cultural responsivity" is understood. Much like Lopez and Bursztyn (2013) suggest, it should diverge from simply focusing on cultural knowledge, towards adopting a critical and self-reflexive awareness of individual cultural biases. Furthermore, the importance of increasing supports to ease the effect of linguistic barriers was often raised, speaking specifically to the need for better utilization of interpreter services.

4.2 Strengths

This study contributes to limited research into newly arrived CALD family's unique experiences of ASD. Hopefully, this study initiates further research and applications to practice, that assist newly arrived CALD families better navigate the ASD process. The research aims of this study required in-depth exploration, achieved through the qualitative design and open-ended questions. Furthermore, the study offers high credibility by adhering to Tracy's (2010) model for quality and excellence in qualitative research. The attempt at triangulation as well as member checking, while unsuccessful, demonstrated a willingness to present, strong reliable data. Similarly, incorporation of an audit trail offered transparency and ensured that researchers were accountable for every step of the research process. In interviewing four different types of service providers the study was able to obtain a significant spectrum of perspective. Finally, in placing substantial focus on language, this study was able to investigate CALD clients in general, while minimising any assumption that all CALD families shared mutual experiences.

4.3 Limitations and future research

Although this study included four types of service providers, many insightful professions were not included (e.g. Paediatricians, psychologists etc). Furthermore, all included services were not represented equally (ie. seven Behavioural Therapists, three Speech Pathologists, one Social Worker, one Teacher/OT). The seven Behavioural Therapists that form the majority of participants, were recruited through primary researcher RP's previous work. This may indicate a selection bias towards Behavioural Therapists which makes it difficult to generalise the results to the wider population of service providers. Furthermore, having such a significant proportion of participants in one profession may have skewed the type of results received. For instance, Chapter one discussed the significance of receptive and expressive language, and variations in how delays present in children with ASD

versus children who are learning a new language. This idea did not appear in the results, however that does not necessarily indicate that it is not relevant. Possibly, the Behavioural Therapists, that dominate the sample, may not have as extensive training as perhaps speech pathologists or developmental psychologists, and were therefore unable to speak to this concept. Future research may consider specifically exploring this aspect of language in CALD children with ASD, with a more varied participant sample.

Although triangulation was attempted in requesting school counsellors, this attempt was unsuccessful, so only one type of professional perspective was offered. Had this triangulation process been successful, including both types of professional services may have offered richer results. Moreover, the perspective of actual CALD community members is unparalleled and one this study was unable to incorporate, meaning it cannot make definitive claims about the experiences of CALD families. Future studies should investigate this avenue to explore the actual lived experiences of newly arrived CALD families navigating the ASD process.

As discussed in section 4.2, the language barrier is the closest thing CALD families of different cultures have in common. Utilising this to investigate CALD families, generally was a key strength. Nevertheless, even linguistic diversity does not exist identically for all communities. For instance, some languages may have more services available than others (i.e. Interpreters/translations). Similarly, while this study's focus on language allowed us to investigate CALD communities as a whole, the variability between different cultures is immense and needs to be acknowledged. While keeping this study general allowed it to explore a wide range of ideas, the lack of cultural specificity may mean that important, culturally nuanced ideas were missed. Future studies should attempt to explore many different cultures specifically to examine their unique challenges.

Further research in this area is required as the current level of literature is limited. As mentioned in 4.2, cultural responsivity training is important possibly with an emphasis on self-reflection and awareness of individual cultural biases. Future research is required investigating the interaction between, service provider's theoretical understanding of cultural diversity, and actual cultural practices. Nevertheless, much of the more relevant research was very recent, possibly indicating that this avenue is finally gaining momentum.

4.4 Implications

ASD research and education is rapidly growing as awareness increases. Similarly, increasing multiculturalism in Australia means that explorations of newly arrived CALD families is a very contemporary topic. The interaction between the two is slowly gaining attention. This study reveals an obvious need for improvement in adapting the ASD process to suit the unique needs and experiences of newly arrived CALD families.

As many of the participants agreed, further action was required to ensure services were suitable for CALD clients. Service providers suggested that much of this responsibility lay with them as professionals. As research such as the present study expands, and the unique challenges of newly arrived CALD families are identified, hopefully practical measures can be incorporated into organisations. Specifically, in relation to assisting families, to navigate services, despite the language barrier. Incorporating especially trained interpreters, in all necessary situations, was cited as a key facilitator for helping newly arrived CALD families. However, service providers can also assist in this respect, by being aware of the existence of the language barrier and therefore mindful that families may not completely understand their propositions.

Though the focus of this study was ASD, it is evident when observing the many resettlement challenges newly arrived CALD families face, and the lack of services to

counteract the language barrier, that the issue may surpass just ASD. The general need for increased support of CALD communities, is too immense to focus specifically on ASD. This is supported significantly through past literature that explores CALD family's experience with health care in their host country (Gard et al, 2017; Rao, Warburton, & Bartlett, 2006; Seeleman, Essink-Bot, Stronks, & Ingleby, 2015; Sulaiman-Hill & Thompson, 2013). As such, despite the necessity for research in CALD ASD, significant research and intervention into supporting newly arrived CALD families in general, is needed.

4.5 Conclusions

This study has provided important insights into the experiences of newly arrived CALD families throughout the ASD process. It is evident that language acts as a significant barrier in all stages of the process for both the parents and the client. While the current process for diagnosing ASD is extensive, and acknowledges its varying presentations, more awareness needs to occur of the CALD client's perspective. This doesn't only suggest a culturally respectful and appropriate service, but also demands the acknowledgement that ASD typical behaviours may not always apply outside a western context. As such, this study has presented a solid foundation upon which to build further, more specific research, to inform the improvement of the ASD journey for newly arrived CALD families.

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Appendix A

Study Flyer – Professionals (Service providers & School Counsellors)

THE UNIVERSITY of ADELAIDE

RECRUITMENT OF RESEARCH PARTICIPANTS

Understanding Autism Spectrum Disorder in refugee and migrant communities

The study will specifically focus on:

- Community understandings of ASD within refugee and migrant communities in Australia
- Cultural appropriateness of current ASD support
- Possible ways to improve diagnosis and service accessibility among the communities

To participate, you will need to;

1. Be over the age of 18
2. Be fluent in English
3. Be a service provider or school counsellor
4. Have some experience/knowledge working with ASD
5. Have some experience/knowledge working with refugee and migrant communities of CALD backgrounds

If you meet these criteria you are invited to take part in a **60-minute interview**, which will involve discussing **your experiences concerning ASD diagnosis and service accessibility** within **refugee and migrant communities**.

If you would like more information, please contact: Ms Makavitage Ravina Anjalee Perera at [redacted]

Or, Dr Clemence Due at [redacted]

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL [redacted]

Appendix B

Study Flyer – Community members

THE UNIVERSITY of ADELAIDE

RECRUITMENT OF RESEARCH PARTICIPANTS

Understanding Autism Spectrum Disorder in refugee and migrant communities

The study will specifically focus on:

- Understanding of ASD within your community
- Community perceptions of ASD.
- Influence of language barriers on ASD diagnosis and service access
- Cultural appropriateness of current ASD support within your community
- Possible ways to improve diagnosis and service accessibility among the communities

To participate, you will need to;

1. Be over the age of 18
2. Be fluent in English
3. Be a member of a culturally and linguistically diverse (CALD) community

If you meet these criteria you are invited to take part in a **60-minute interview**, which will involve discussing **your communities' experiences** of **ASD diagnosis and service accessibility** within **CALD refugee and migrant communities**.

If you would I ke more information, please contact: Ms Makavitage Ravina Anjalee Perera at [redacted]

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL [redacted]

Appendix C

Information Sheet – Professionals (Service providers & School Counsellors)

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Understanding Autism Spectrum Disorder in Australia's refugee and migrant communities
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: [redacted]
PRINCIPAL INVESTIGATOR: Dr Clemence Due
STUDENT RESEARCHER: Makavitage Ravina Anjalee Perera (Ravina)
STUDENT'S DEGREE: Honours degree of a bachelor of Psychological Science

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This research project is about the refugee and migrant communities of Australia who come from culturally and linguistically diverse (CALD) backgrounds. Specifically, the study aims to explore to what degree Autism Spectrum disorder (ASD) is considered or how it is understood in these communities. The project wants to investigate what possible barriers or facilitators exist in diagnosing ASD within these communities.

Who is undertaking the project?

This project is being conducted by Makavitage Ravina Anjalee Perera (Ravina). This research will form the basis for an Honours degree of a Bachelor of Psychological Science at the University of Adelaide under the supervision of Dr Clemence Due.

Why am I being invited to participate?

You are being invited as a professional who has working experience with refugee or migrant individuals of CALD backgrounds including in relation to ASD.

What am I being invited to do?

You are being invited to take part in an approximately 60-minute interview which will include questions exploring your opinions, based on your professional experience, about understandings of ASD within refugee and migrant communities and any barriers or facilitators to service access.

The interviews will be located in a mutually agreed upon location or over the phone or skype.

After the interview, you can read your interview transcript if you wish. Please let Ravina know if you would like to do so and she will send you a copy.

These interviews will be audio recorded, transcribed and then analysed by Ravina. You will be given a pseudonym to retain your anonymity throughout the study and the final paper.

Are there any risks associated with participating in this project?

There are no foreseeable risks in your participation in this study.

What are the potential benefits of the research project?

The results of this study may assist in providing evidence concerning more culturally appropriate ASD support for those in refugee and migrant communities of CALD backgrounds.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time.

What will happen to my information?

You will have complete confidentiality. The audio recordings of the interview will be stored on a password protected computer in, supervisor Dr Clemence Due's office at the university of Adelaide's school of Psychology. All information will be removed from any portable recording device. From transcription, you will be given a pseudonym to replace your given name, and only this pseudonym will be referred to when in the paper when referring to your interview. No personal details will be included in the paper. All data from this study will also be kept securely in Dr Due's office for a period of 7 years.

The final results of this study will be written as partial fulfillment of an Honours in Psychology degree undertaken by Ravina. The study will be written with intent to potentially submit for publication in a peer-reviewed journal.

We will also write a short final report on the basis of the findings. If you would like to receive a copy of this report, please let Ravina know.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

You can also view and make comments on your transcript if you wish.

Who do I contact if I have questions about the project?

You may contact Dr Clemence Due, the research supervisor should you wish to discuss the project and/or your involvement int it. [redacted]

What if I have a complaint or any concerns?

The study has been approved by the Human Research ethics Sub Committee at the University of Adelaide (approval number: 19/21). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. Contact the School of Psychology Human Research Ethics Sub-Committee's Secretariat on phone +61 8 8313 4936 or by email to hrec@adelaide.edu.au if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you are interested in participating in this study, please get in contact with Ravina at [redacted] We will send you a consent form to read and sign, and will further correspond with you to organise the most suitable time for an interview, and a mutually agreed location (unless you desire a phone interview).

Yours sincerely,

Dr Clemence Due and,
Ms Makavitage Ravina Anjalee Perera (Ravina)

Appendix D

Information Sheet – Community members

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Understanding Autism Spectrum Disorder in Australia's refugee and migrant communities
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: [redacted]
PRINCIPAL INVESTIGATOR: Dr Clemence Due
STUDENT RESEARCHER: Makavitage Ravina Anjalee Perera (Ravina)
STUDENT'S DEGREE: Honours degree of a bachelor of Psychological Science

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This research project is about the refugee and migrant communities of Australia who come from culturally and linguistically diverse (CALD) backgrounds. Specifically, the study aims to explore understandings of Autism Spectrum Disorder (ASD) within communities as well as barriers or facilitators to accessing services.

Who is undertaking the project?

This project is being conducted by Makavitage Ravina Anjalee Perera (Ravina). This research will form the basis for an Honours degree of a Bachelor of Psychological Science at the University of Adelaide under the supervision of Dr Clemence Due.

Why am I being invited to participate?

You are being invited as a member of a CALD community, and we would value your input into this research project. You are being invited to discuss how your community understands ASD, as well as any barriers or facilitators that may exist in gaining support.

What am I being invited to do?

You are being invited to take part in an approximately 60-minute interview which will include questions exploring your understandings, based on your community experience, about ASD for children and families within your community.

The interviews can be conducted at a location convenient to you for example a library, café or at The University of Adelaide, or we can conduct the interview over the phone or skype.

After the interview, you can read your interview transcript if you wish. Please let Ravina know if you would like to do so and she will send you a copy.

These interviews will be audio recorded, transcribed and then analysed by Ravina. You will be given a pseudonym to retain your anonymity throughout the study and the final paper.

Are there any risks associated with participating in this project?

There are no foreseeable risks in your participation in this study. However, if you were to express any concerns regarding ASD in your community, we will provide you with a list of services that you can contact.

What are the potential benefits of the research project?

The results of this study may assist in opening avenues into providing better more culturally appropriate ASD support for those in various refugee and migrant communities in Australia.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time.

What will happen to my information?

You will have complete confidentiality. The audio recordings of the interview will be stored on a password protected computer in, supervisor Dr Clemence Due's office at the University of Adelaide's school of Psychology. All information will be removed from any portable recording device. From transcription, you will be given a pseudonym to replace your given name, and only this pseudonym will be referred to when in the paper when referring to your interview. No personal details will be included in the paper. All data from this study will also be kept securely in Dr Due's office for a period of 7 years.

The final results of this study will be written as partial fulfillment of an Honours in Psychology degree undertaken by Ravina. The study will be written with intent to potentially submit for publication in a peer-reviewed journal.

We will also write a short final report on the basis of the findings. If you would like to receive a copy of this report, please let Ravina know.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

You can also view and make comments on your transcript if you wish.

Who do I contact if I have questions about the project?

You may contact Dr Clemence Due, the research supervisor should you wish to discuss the project and/or your involvement int it. [redacted]

What if I have a complaint or any concerns?

The study has been approved by the Human Research ethics Sub Committee at the University of Adelaide (approval number: [redacted] If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. Contact the School of Psychology Human Research Ethics Sub-Committee's Secretariat on phone +61 8 8313 4936 or by email to hrec@adelaide.edu.au if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you are interested in participating in this study, [redacted] We will send you a consent form to read and sign, and will further correspond with you to organise the most suitable time for an interview, and a mutually agree location (unless you desire a phone interview).

Yours sincerely,

Dr Clemence Due and,
Ms Makavitage Ravina Anjalee Perera (Ravina)

Appendix E

Consent form – Professionals (Service providers & School Counsellors)

Human Research Ethics Committee (HREC)

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	Understanding Autism Spectrum Disorder in Australia's refugee and
Ethics Approval Number:	[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any benefit to me.

4. I agree to participate in the activities outlined in the participant information sheet.

   - 60-Minute Interview

5. I agree to be:
   Audio recorded ☐ Yes ☐ No

6. I understand that I am free to withdraw from the project at any time and that my identity will be protected, with a pseudonym to replace my name.

7. I wish to view a transcription of my interview: ☐ Yes ☐ No

8. I have been informed that the information gained in the project may be published as a thesis as partial fulfilment of an honours in psychology degree, and that the study will be written with the intent to potentially submit for publication in a peer reviewed journal.

9. I have been informed that in the published materials I will not be identified, and my personal results will not be divulged.

10. I understand my information will only be disclosed according to the consent provided, except where disclosure is required by law.

11. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: _____ Signature: _____

Date: _____

Researcher/Witness to complete:

I have described the nature of the research to

_____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____ Position: _____

Date: _____

Appendix F

Consent form – Community members

Human Research Ethics Committee (HREC)

THE UNIVERSITY of ADELAIDE

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	Understanding Autism Spectrum Disorder in Australia's refugee and
Ethics Approval Number:	[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any benefit to me.

5. I agree to participate in the activities outlined in the participant information sheet.

    - 60-Minute Interview

6. I agree to be:
   Audio recorded ☐ Yes ☐ No

7. I understand that I am free to withdraw from the project at any time and that my identity will be protected, with a pseudonym to replace my name.

8. I wish to view a transcription of my interview: ☐ Yes ☐ No

9. I have been informed that the information gained in the project may be published as a thesis as partial fulfilment of an honours in psychology degree, and that the study will be written with the intent to potentially submit for publication in a peer reviewed journal.

10. I have been informed that in the published materials I will not be identified, and my personal results will not be divulged.

11. I understand my information will only be disclosed according to the consent provided, except where disclosure is required by law.

12. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: _____ Signature: _____

Date: _____

Researcher/Witness to complete:

I have described the nature of the research to

_____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____ Position: _____

Date: _____

Appendix G

Interview Schedule

Open ended questions

1. How do you think families tend to think about ASD?
2. Have you been around a child upon diagnosis of ASD? – how do you work with families upon receiving a diagnosis?
3. In your opinion how is a diagnosis of Autism received from those of CALD backgrounds?
4. What types of barriers and facilitators are there to service access concerning ASD?
5. What factors currently exist, that you believe assist CALD parents in navigating ASD services?
6. What are the necessary components in providing a culturally appropriate ASD service for CALD families?
7. I'm particularly interested in language in relation to ASD, could you reflect a little bit on the role of language for culturally and linguistically diverse families through the diagnosis process?
8. Do you think that ASD diagnosis and support translates well across languages and culture when attempting to assist recent migrants or refugees or CALD backgrounds?
9. What possible suggestions do you have to improve ASD services for refugee and migrant communities of CALD backgrounds?
10. Do you have any feedback on any of the questions?